

# Understanding Temporal Tensions in Informal Care for AI Design

ZHUOYANG LI, Eindhoven University of Technology, Netherlands

MAARTEN HOUBEN, Eindhoven University of Technology, Netherlands

DANIEL TETTEROO, Eindhoven University of Technology, Netherlands

Informal care relationships form a critical foundation of chronic disease management, sustained through long-term effort and shifting responsibilities among family members and social networks. Although HCI has introduced a growing range of systems for informal care, many are designed around episodic interactions or stable task roles, limiting their relevance for care that unfolds relationally over time. In this position paper, we use temporality as an analytic lens to examine this mismatch. Building on Reddy et al.'s framework of temporal trajectories, rhythms, and horizons, we reinterpret these dimensions in informal chronic care and describe three resulting tensions: reconfiguring care roles across chronic illness progression, misalignments between everyday caregiving routines, and ongoing relational commitments oriented toward uncertain futures. From these tensions, we discuss implications for AI systems, including supporting the revisiting of care relationships over time, allowing adjustment as care routines evolve, and enabling discussion and preparation on possible future situations.

CCS Concepts: • **Human-centered computing** → **HCI theory, concepts and models**.

## ACM Reference Format:

Zhuoyang Li, Maarten Houben, and Daniel Tetteroo. 2026. Understanding Temporal Tensions in Informal Care for AI Design. In *Proceedings of Proceedings of the 2026 CHI Conference on Human Factors in Computing Systems (CHI '26)*. ACM, New York, NY, USA, 6 pages. <https://doi.org/XXXXXXX.XXXXXXX>

## 1 Introduction

Informal care relationship constitutes a largely invisible yet essential foundation of chronic disease management, as it offers ongoing practical, emotional, and social support beyond clinical encounters [14, 17]. Such relationships encompass a web of family members, friends, peers, and other social ties who sustain care through the everyday negotiation of shared lives, values, and vulnerabilities over time [16, 18, 21, 23].

Within HCI, researchers have explored a growing range of systems that intersect with informal relationship-centered care (RCC), including companionship agents, monitoring technologies, coordination tools, and mediation supports [11, 15, 20, 22, 25, 28]. Many of these interventions provide meaningful assistance in specific situations or moments of care. However, they often target discrete needs, such as task assistance, safety monitoring, or communication facilitation, rather than supporting enduring socio-emotional aspects of informal RCC [29].

Chronic illness care, by contrast, is organized temporally: conditions progress, caregiving roles redistribute, routines are continually reconfigured, and relationships adjust to changing dependence [1, 21]. The challenge, therefore, extends

---

Authors' Contact Information: Zhuoyang Li, Department of Industrial Design, Eindhoven University of Technology, Eindhoven, Noord-Brabant, Netherlands, [z.li7@tue.nl](mailto:z.li7@tue.nl); Maarten Houben, Department of Industrial Design, Eindhoven University of Technology, Eindhoven, Noord-Brabant, Netherlands, [m.houben1@tue.nl](mailto:m.houben1@tue.nl); Daniel Tetteroo, Department of Industrial Design, Eindhoven University of Technology, Eindhoven, Noord-Brabant, Netherlands, [d.tetteroo@tue.nl](mailto:d.tetteroo@tue.nl).

---

Permission to make digital or hard copies of all or part of this work for personal or classroom use is granted without fee provided that copies are not made or distributed for profit or commercial advantage and that copies bear this notice and the full citation on the first page. Copyrights for components of this work owned by others than the author(s) must be honored. Abstracting with credit is permitted. To copy otherwise, or republish, to post on servers or to redistribute to lists, requires prior specific permission and/or a fee. Request permissions from [permissions@acm.org](mailto:permissions@acm.org).

© 2026 Copyright held by the owner/author(s). Publication rights licensed to ACM.

Manuscript submitted to ACM

Manuscript submitted to ACM

1

beyond supporting discrete needs to supporting timing, pacing, and persistence. Systems must accommodate when intervention becomes appropriate [22], how technologies fit the rhythms of everyday care [2], and how responsibilities endure across transitions [8, 25]. From this perspective, the central difficulty in introducing artificial intelligence (AI) into informal RCC is not insufficient intelligence but insufficient temporal sensitivity. Systems that appear effective in temporally bounded evaluations may falter as relationships evolve, routines fluctuate, and the future remains uncertain.

Temporality thus offers a critical analytic lens for understanding the relational dynamics and how AI might better sustain relational continuity across the unfolding course of chronic illness [26]. To advance this argument, we adopt the vocabulary in Reddy et al.'s work [19]—temporal trajectory, temporal rhythm, and temporal horizon—to characterize the asymmetrical and continually shifting context of informal RCC. Drawing from these perspectives, we offer provocations for AI systems that seek not only to assist in isolated moments but to remain sensitive and adaptable to the relational-temporal dynamics of chronic care.

## 2 Temporal Tensions in Informal Relationship-Centered Chronic Care (RCC)

In studies of collaborative medical information work, Reddy et al. [19] propose three temporal dimensions for understanding how medical work is coordinated, and responsibilities are distributed: **temporal trajectories**, **temporal rhythms**, and **temporal horizons**. In their original context, temporal trajectories describe the understanding of patient illness over time, including diagnosis, treatment, and prognosis. Temporal rhythms highlight the recurring patterns and cycles through which clinical work is organized, such as routines of monitoring, scheduled encounters, and periodic interventions. Temporal horizons, in turn, reflect the flexibility or rigidity of the time frame available to complete tasks, which varies with patient stability [19].

While Reddy et al. developed this framework to analyze the organizational features of medical information work, we extend these temporal dimensions into the context of informal RCC for chronic conditions. Unlike formal care settings where work is structured through explicit schedules, documented plans, and institutionally coordinated roles, informal RCC is embedded in the ongoing everyday life. We therefore reinterpret Reddy et al.'s temporal dimensions not as descriptors of institutional coordination but as relational-temporal tensions through which care identities, responsibilities, and expectations are continually renegotiated.

To ground these temporal lenses in lived experience, we draw on vignettes from a pilot study with Ann (pseudonym), the wife of a person living with dementia. The study involved a collage activity on imagined futures in dementia, held at a community centre that hosts day care activities. Ann described her experiences as her husband's condition worsened and he transitioned into residential care. We use her experience as a running thread to illustrate each of the three temporal perspectives, while also highlighting the broader tensions drawn from previous studies.

### 2.1 Temporal Trajectories: Reconfiguring Care Roles Across Chronic Illness Progression

**Vignette I.** *Before the dementia became severe, Ann's husband handled digital tasks such as taxes and email. As his condition progressed, he could no longer manage them, so Ann tried to take over. Because she struggled with the tasks and made mistakes, their adult children later took the devices away from her and managed these digital tasks for her.*

This vignette highlights how caregiving roles evolve along with the illness trajectory and role transfer towards a broader care network. Ann was the primary caregiver for her husband, but on the digital task, she became the care

recipient. Ann’s children were not initially central roles in caregiving, but their involvement increased as caregiving demands accumulated and new forms of assistance became necessary.

In informal chronic care, relationships are evolving along with the gradually unfolding illness trajectory [7, 26]. Chronic conditions often extend over many years, and caregiving responsibilities shift as conditions change and support needs expand. For example, Shi et al. describe dementia caregiving as unfolding through early, middle, and late phases, each associated with distinct emotional burdens, information needs, and forms of care negotiation [21]. Xu et al. further emphasize that caregiving trajectories are often anchored around life-changing events, through which caregivers must continually reinterpret their circumstances [26]. Similar trajectory-based role evolution also appears in peer support settings: in many online support groups, participants often move over time from being information “seekers” to becoming “storytellers,” “emotional supporters,” and even “welcomers” of newcomers [27]. Thus, chronic illness trajectories do not simply represent biomedical changes, but a long-term relational process through which care networks expand, actors enter and exit, responsibilities are redistributed, and identities are continuously rewritten over time.

These relational shifts contrast with how many AI systems conceptualize caregiving. Technologies often assume fixed user roles (e.g., “caregiver” vs. “care recipient”) and stable task profiles [9]. As illness trajectories unfold, however, responsibilities are continually renegotiated in practice, requiring families to decide who can manage particular activities and when additional support becomes necessary. Rather than offering isolated guidance, AI systems could assist this ongoing coordination by helping families track changes over time, revisit prior arrangements, and notice emerging shifts in caregiving responsibilities [3]. In doing so, systems may also support a shared understanding of illness progression grounded in the evolving organization of care.

## 2.2 Temporal Rhythms: Misalignments Across Everyday Lives

**Vignette II.** *After her husband moved into residential care, Ann’s caregiving did not end. She visited him almost every day and maintained regular communication with the care staff. After returning home from these visits, she often chose to go to bed early, avoiding the loneliness of being in an empty house.*

Informal care relationships are shaped not only by long-term illness trajectories but also sustained through recurring patterns of everyday life. In this vignette, caregiving continues after residential transition and becomes organized around repeated visits, handovers, and routines structured by presence and absence. Prior work describes caregiving rhythms as emerging through ongoing temporal coordination of activities. For example, Nikkhah et al. found that during extended pediatric cancer hospitalization, families developed daily and weekly cycles (e.g., synchronizing information during morning rounds or enacting “shift-change” practices) to sustain care across fragmented institutional schedules [16].

These temporal adjustments also appear in micro-level scheduling practices around medications, appointments, and ongoing monitoring [2]. However, the patterns of patients’ physical conditions often diverge from standardized care cycles [5, 6]. For instance, chronic fatigue or mood disorders involve fluctuations that repeatedly disrupt fixed schedules [4, 15]. Informal care, therefore, requires ongoing alignment across family routines, symptom dynamics, and institutional time structures.

The central tension is that informal caregiving unfolds through uneven and relational temporal patterns, whereas technological and institutional systems are typically organized around stable and temporally predictable points for providing support. Assistance delivered at inappropriate moments can be experienced as intrusive or add coordination burden, particularly in emotional support contexts [22]. Instead of constant engagement or generic reminders, AI systems in informal RCC can provide support that depends on when it is offered and fits within caregivers’ everyday

routines. Work on End-User Development (EUD) highlights the importance of aligning system behavior with evolving practices by allowing users to re-configure how and when technologies act [24]. In this context, AI may enable families to adjust reminders, monitoring, and support through natural language, accommodating changing symptom patterns and household routines rather than fixed schedules, while also helping translate these routines into fixed time structures, such as clinical appointments, medication schedules, and reporting requirements.

### 2.3 Temporal Horizons: Relationship as Long-term Commitment Under Uncertain Futures

*Vignette III. As Ann’s husband’s condition worsened, she described him as “just like toddlers, you really have to keep them busy and doing something. It is not a relationship anymore, because he becomes a child again.”*

Ann’s case shows that their spousal relationship is no longer grounded in mutual partnership, but is gradually reframed through long-term guardianship, enduring responsibility, and emotional uncertainty. Unlike clinical care, which often operates within bounded timeframes of visits, interventions, or treatment cycles, informal care relationships extend across long-term futures shaped by maintenance, vigilance, adaptation, or possible decline. Whether managing diabetes through lifelong routines, navigating cancer survivorship through continued monitoring, or supporting dementia care through progressive declines, informal caregivers often face prolonged responsibility without clear endpoints [1, 2, 8]. For example, in dementia care, family members may initially experience anticipatory grief at diagnosis [13], which then unfolds into iterative grief as ongoing changes in conditions gradually transform both the person and the relationship [12]. Therefore, we emphasize that temporal horizons foreground informal care relationships as extending toward futures that remain unresolved and difficult to clearly define.

The core tension here is not simply that responsibilities change, but that **the future of caregiving cannot be fully specified or closed**. Therefore, we argue that the opportunity for AI is not to predict the future or provide definitive answers, but to **help caregivers better imagine and prepare for different possibilities**. For example, AI may support families in discussing plausible care scenarios, such as how responsibilities might shift, what living transitions may arise, or what forms of support could become necessary. AI may also help by synthesizing experiences shared in online peer communities, allowing caregivers to learn from how others have navigated similar uncertainties and turning points [10]. In this way, AI does not eliminate uncertainty, but may help make long-term futures more discussable, less isolating, and easier to prepare for within informal chronic care relationships.

### 3 Conclusion

In this position paper, building on Reddy et al.’s framework of temporal trajectories, rhythms, and horizons [19], we propose three temporal lenses for understanding informal care relationships in chronic care contexts. By resituating these temporal dimensions within everyday care, we highlighted how informal care is shaped by gradual role transitions across illness progression, ongoing coordination work embedded in uneven daily rhythms, and long-term relational commitments oriented toward uncertain futures. We further outlined potential directions for AI systems that are informed by these temporal lenses, emphasizing opportunities for supporting the revisiting of care relationships over time, allowing adjustment as care routines evolve, and enabling discussion and preparation on possible future situations. Importantly, we do not position AI as a solution to the inherent uncertainties of chronic care, but as a potential resource for engaging with them more reflectively and sustainably. We hope this work encourages further discussion on how temporality can be more centrally considered in the design of AI systems that engage with the long-term, relational nature of informal care.

## References

- [1] Elizabeth A. Ankrah, Megh Marathe, Arpita Bhattacharya, Anamara Ritt-Olson, Joel E. Milam, Lilibeth Torno, and Gillian R. Hayes. 2023. Plan For Tomorrow: The Experience of Adolescent and Young Adult Childhood Cancer Survivors as they Transition to Adult Care. *Proc. ACM Hum.-Comput. Interact.* 7, CSCW2, Article 352 (Oct. 2023), 27 pages. doi:10.1145/3610201
- [2] Andrea Barbarin, Tiffany C. Veinot, and Predrag Klasnja. 2015. Taking our Time: Chronic Illness and Time-Based Objects in Families. In *Proceedings of the 18th ACM Conference on Computer Supported Cooperative Work & Social Computing* (Vancouver, BC, Canada) (CSCW '15). Association for Computing Machinery, New York, NY, USA, 288–301. doi:10.1145/2675133.2675200
- [3] Andrea M Barbarin, Predrag Klasnja, and Tiffany C Veinot. 2016. Good or bad, ups and downs, and getting better: Use of personal health data for temporal reflection in chronic illness. *International Journal of Medical Informatics* 94 (2016), 237–245. <https://doi.org/10.1016/j.ijmedinf.2016.06.011>
- [4] Ryan David Bowler, Benjamin Bach, and Larissa Pschetz. 2022. Exploring Uncertainty in Digital Scheduling, and The Wider Implications of Unrepresented Temporalities in HCI. In *Proceedings of the 2022 CHI Conference on Human Factors in Computing Systems* (New Orleans, LA, USA) (CHI '22). Association for Computing Machinery, New York, NY, USA, Article 140, 12 pages. doi:10.1145/3491102.3502107
- [5] Michael Bury. 1982. Chronic illness as biographical disruption. *Sociology of health & illness* 4, 2 (1982), 167–182.
- [6] Kathy Charmaz. 1991. *Good days, bad days: The self in chronic illness and time*. Rutgers University Press.
- [7] Juliet M Corbin. 1998. The Corbin and Strauss chronic illness trajectory model: an update. *Research and Theory for Nursing Practice* 12, 1 (1998), 33.
- [8] Maarten Houben, Rens Brankaert, Maudy Gosen, Veerle van Overloop, and Wijnand IJsselsteijn. 2024. Design Opportunities for Care Transitions in Dementia: Understanding Informal Caregivers' Experiences Through a Practice-Informed Approach. In *Proceedings of the 2024 CHI Conference on Human Factors in Computing Systems* (Honolulu, HI, USA) (CHI '24). Association for Computing Machinery, New York, NY, USA, Article 214, 13 pages. doi:10.1145/3613904.3642556
- [9] Long-Jing Hsu and Chia-Fang Chung. 2024. Dancing with the Roles: Towards Designing Technology that Supports the Multifaceted Roles of Caregivers for Older Adults. In *Proceedings of the 2024 CHI Conference on Human Factors in Computing Systems* (Honolulu, HI, USA) (CHI '24). Association for Computing Machinery, New York, NY, USA, Article 1010, 12 pages. doi:10.1145/3613904.3642728
- [10] Jina Huh and Mark S. Ackerman. 2012. Collaborative help in chronic disease management: supporting individualized problems. In *Proceedings of the ACM 2012 Conference on Computer Supported Cooperative Work* (Seattle, Washington, USA) (CSCW '12). Association for Computing Machinery, New York, NY, USA, 853–862. doi:10.1145/2145204.2145331
- [11] Jazette Johnson, Hira Jamshed, Rachael Zuppke, Amanda Leggett, Emily Mower Provost, and Robin N. Brewer. 2025. "I Felt Listened to": Evaluating an AI-Powered Reflection Tool for Care Partners. 18, 3, Article 11 (July 2025), 35 pages. doi:10.1145/3731562
- [12] Gail Kenning and Cathy Treadaway. 2018. Designing for Dementia: Iterative Grief and Transitional Objects. *Design Issues* 34, 1 (01 2018), 42–53. doi:10.1162/DESI\_a\_00475
- [13] Natashe Lemos Dekker. 2023. Anticipatory grief in dementia: an ethnographic study of loss and connection. *Culture, Medicine, and Psychiatry* 47, 3 (2023), 701–721.
- [14] Niccolò Morelli, Serena Barello, Maria Mayan, and Guendalina Graffigna. 2019. Supporting family caregiver engagement in the care of old persons living in hard to reach communities: A scoping review. *Health & social care in the community* 27, 6 (2019), 1363–1374.
- [15] Elizabeth L. Murnane, Tara G. Walker, Beck Tench, Stephen Volda, and Jaime Snyder. 2018. Personal Informatics in Interpersonal Contexts: Towards the Design of Technology that Supports the Social Ecologies of Long-Term Mental Health Management. *Proc. ACM Hum.-Comput. Interact.* 2, CSCW, Article 127 (Nov. 2018), 27 pages. doi:10.1145/3274396
- [16] Sarah Nikkhah, Swaroop John, Krishna Supradeep Yalamarti, Emily L. Mueller, and Andrew D. Miller. 2022. Family Care Coordination in the Children's Hospital: Phases and Cycles in the Pediatric Cancer Caregiving Journey. *Proc. ACM Hum.-Comput. Interact.* 6, CSCW2, Article 296 (Nov. 2022), 30 pages. doi:10.1145/3555187
- [17] Mike R Nolan, Sue Davies, Jayne Brown, John Keady, and Janet Nolan. 2004. Beyond 'person-centred' care: a new vision for gerontological nursing. *Journal of clinical nursing* 13 (2004), 45–53.
- [18] Leonard I Pearlin, Joseph T Mullan, Shirley J Semple, and Marilyn M Skaff. 1990. Caregiving and the stress process: An overview of concepts and their measures. *The gerontologist* 30, 5 (1990), 583–594.
- [19] Madhu C Reddy, Paul Dourish, and Wanda Pratt. 2006. Temporality in medical work: Time also matters. *Computer Supported Cooperative Work* (CSCW) 15, 1 (2006), 29–53. <https://doi.org/10.1007/s10606-005-9010-z>
- [20] Zachary Shea, Zaina Aljallad, David Taylor, Chhaya Chouhan, and Pamela J. Wisniewski. 2019. Carebit: A Mobile App for Remote Informal Caregiving. In *Companion Publication of the 2019 Conference on Computer Supported Cooperative Work and Social Computing* (Austin, TX, USA) (CSCW '19 Companion). Association for Computing Machinery, New York, NY, USA, 23–27. doi:10.1145/3311957.3359511
- [21] Jiayue Melissa Shi, Keran Wang, Dong Whi Yoo, Ravi Karkar, and Koustuv Saha. 2025. Balancing Caregiving and Self-Care: Exploring Mental Health Needs of Alzheimer's and Dementia Caregivers. *Proc. ACM Hum.-Comput. Interact.* 9, 7, Article CSCW374 (Oct. 2025), 36 pages. doi:10.1145/3757555
- [22] Diva Smriti. 2023. Bringing Emotions into Practice: The Role of AI in Supporting Emotional Work in Informal Caregiving. In *Companion Publication of the 2023 ACM Designing Interactive Systems Conference* (Pittsburgh, PA, USA) (DIS '23 Companion). Association for Computing Machinery, New York, NY, USA, 37–40. doi:10.1145/3563703.3593066
- [23] Yuling Sun, Sam Addison Ankenbauer, Zhifan Guo, Yuchen Chen, Xiaojuan Ma, and Liang He. 2025. Rethinking Technological Solutions for Community-Based Older Adult Care: Insights from 'Older Partners' in China. *Proc. ACM Hum.-Comput. Interact.* 9, 2, Article CSCW160 (May 2025),

- 36 pages. doi:10.1145/3711058
- [24] Daniel Tetteroo, Paul Vreugdenhil, Ivor Grisel, Marc Michielsen, Els Kuppens, Diana Vanmulken, and Panos Markopoulos. 2015. Lessons Learnt from Deploying an End-User Development Platform for Physical Rehabilitation. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems* (Seoul, Republic of Korea) (*CHI '15*). Association for Computing Machinery, New York, NY, USA, 4133–4142. doi:10.1145/2702123.2702504
- [25] Lusi Ruth Wang and Sang-won Leigh. 2025. *Companionship to Mediation: Rethinking the Role of AI in Informal Older Adult Caregiving*. Association for Computing Machinery, New York, NY, USA, 471–476. <https://doi.org/10.1145/3715668.3736350>
- [26] Kefan Xu, Cynthia M. Baseman, Nathaniel Swinger, Myeonghan Ryu, and Rosa I. Arriaga. 2025. Understanding the Temporality of Informal Caregivers' Sense-Making on Conflicts and Life-Changing Events through Online Health Communities. *Proc. ACM Hum.-Comput. Interact.* 9, 7, Article CSCW338 (Oct. 2025), 36 pages. doi:10.1145/3757519
- [27] Diyi Yang, Robert E. Kraut, Tenbroeck Smith, Elijah Mayfield, and Dan Jurafsky. 2019. Seekers, Providers, Welcomers, and Storytellers: Modeling Social Roles in Online Health Communities. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems* (Glasgow, Scotland UK) (*CHI '19*). Association for Computing Machinery, New York, NY, USA, 1–14. doi:10.1145/3290605.3300574
- [28] Yihan Yu and David W. McDonald. 2023. Conflicts of Control: Continuous Blood Glucose Monitoring and Coordinated Caregiving for Teenagers with Type 1 Diabetes. *Proc. ACM Hum.-Comput. Interact.* 7, CSCW2, Article 306 (Oct. 2023), 32 pages. doi:10.1145/3610097
- [29] Tamara Zubatiy, Niharika Mathur, Larry Heck, Kayci L. Vickers, Agata Rozga, and Elizabeth D. Mynatt. 2023. "I don't know how to help with that" - Learning from Limitations of Modern Conversational Agent Systems in Caregiving Networks. 7, CSCW2, Article 321 (Oct. 2023), 28 pages. doi:10.1145/3610170